

**The Catastrophic Illness in Children Relief Fund**

*When other resources end, we begin.*

## **The Catastrophic Illness in Children Relief Fund**

### **Annual Report: FY 2005**



**A NEW SENSE OF HOPE WHEN YOU NEED IT MOST.**

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## LETTER FROM THE COMMISSION CO-CHAIRS:

February 2007

On behalf of our fellow Commissioners, we are pleased to provide this annual report on the Catastrophic Illness in Children Relief Fund.

In 2005, the Fund completed its fifth year of supporting some of the most vulnerable children in Massachusetts. We are very proud of the work we do, as one of only two Funds of this kind in the nation. Through the work of our Commissioners, and supported by the excellent staff at the Department of Public Health, we have served over 400 children from all across the state.

The Fund provides critical financial support to families struggling to care for children with extensive medical needs. This financial support can make an enormous difference in a family's ability to care for a sick child in the community instead of seeking more institutional care. In many instances, the Fund "fills the gaps" left by traditional insurance coverage, helping families afford specialized equipment, providing transportation resources, and assisting with home and vehicle modifications for children with mobility impairments.

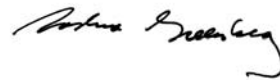
Our work is labor intensive because we seek to help stabilize families with critically ill children over the long term. The case management provided by DPH staff is critical to assuring that families can access additional resources throughout the state to supplement Fund support. In this way, we leverage significant in-kind and financial support from other providers. The testimonials of parents found throughout this report speak to the remarkable differences we have made in children's lives.

We welcome your comments, feedback and ideas as we seek to improve our ability to serve children and families.

Yours truly,



Patricia Roche, M.Ed., J.D.  
Co-Chair



Joshua Greenberg, J.D.  
Co-Chair

## **EXECUTIVE SUMMARY**

### **Purpose of the Fund**

The Catastrophic Illness in Children Relief Fund (CICRF) was established by legislation for FY 2001 (year beginning July 1, 2000). The purpose of the Fund is to reimburse families for catastrophic medical and medically related expenses that are not covered by any insurer or other program.

Since the Fund's inception, it has provided \$5.5M in reimbursements to the families of 405 catastrophically ill children, from a variety of backgrounds. Massachusetts families with children under 19 years of age, whose medical and related expenses for one child exceed 10% of the first \$100,000 plus 15% thereafter of the family's annual income, are eligible to apply for assistance from the CICRF.

### **Fiscal Year 2005 Summary**

- During FY 05, 186 families received a total of \$1.2M in reimbursements, with an average reimbursement of approximately \$6,620 per family. A total of 68 new families were found eligible and received reimbursement, in addition to 118 families that were deemed eligible in previous years.
- The children who have been assisted by the CICRF have a variety of different diagnoses, typically come from low-income families, and almost all have some form of health insurance coverage. Most notably, during FY 05, 62.4% of the families who received assistance had annual incomes of less than 200% of the federal poverty level, and 39.7% of the children who were helped during FY 05 were under the age of five.
- The CICRF supports a wide variety of services, including medical equipment, medical services, hospital and physician services, medications, family support, and home and vehicle modifications that enable children to remain at home and a part of their communities, rather than in residential or institutional care.

### **Financial Status of the Fund**

At the close of FY 05 the Fund maintained a positive balance of \$2.8M.

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## I. INTRODUCTION

The Catastrophic Illness in Children Relief Fund (CICRF) was established by state legislation in July 2000 to help families bear the excessive financial burdens associated with the care of children with high medical and related expenses. It provides last resort financial assistance for families in Massachusetts that are struggling to pay for medical or medically-related expenses not covered by a private insurer, federal or state health care assistance, or any other financial source. Since FY 2001, the Fund served hundreds of families from across Massachusetts, providing basic support to allow children to remain at home and be cared for in their communities.

The CICRF was established within the Department of Public Health, in accordance with the Massachusetts General Laws, Chapter 29, Section 2ZZ, and administered by the CICRF Commission, which was established and is governed by Chapter 111K of the Massachusetts General Laws. A catastrophic illness is defined as “any illness or condition treated at a pediatric specialty hospital, including ambulatory care and services provided by or ordered through such a hospital, the medical and related expenses of which are not covered by any other state or federal program...or any insurance contract and which exceed 10 percent of the first \$100,000 of annual income of a family and 15 percent of any family income in excess of \$100,000.”

The Fund is overseen by a Commission consisting of 11 members (4 state agency ex-officio members and 7 public members), and is staffed by the Department of Public Health. The Fund is financed by quarterly transfers from the Medical Security Trust Fund, if sufficient funds are available. (See section IV for more detailed information about the funding of the CICRF.)

Since its inception, the CICRF has provided funds to **405** children with a wide array of medical conditions and diagnoses. Their families come from across the state, from all income levels, and are largely insured either through private coverage and/or MassHealth. Families have been reimbursed for a variety of eligible expenses, including hospital and physician services, medication, medical equipment and supplies, travel and lodging, funeral expenses, special therapies, and home and vehicle modifications.

The cost of caring for a chronically ill child can be overwhelming, even to a family with health insurance. High insurance premiums, deductibles and co-payments, combined with medical and medically related expenses incurred because of coverage limitations and exclusions, can result in a serious drain of a family’s financial resources. The bills acquired can send the family into extreme debt and cause severe emotional stress. In fact, studies have shown that the leading cause of personal bankruptcy in the U.S. is medical bills resulting from an illness (even with health insurance coverage). One study

showed that sixty-one percent of these families in a “medical” bankruptcy went without needed medical care.<sup>1</sup>

The impact of a child’s illness can have severe ripple effects. The time and energy necessary to care for a sick child often place further debilitating strain on a family and often results in loss of employment of one or both parents. In such situations, the family loses not only income, but frequently loses health benefits as well (since access to health insurance is often through one’s employer). The sick child is then either uninsured, or the family has the additional burden of affording the full cost of insurance premiums. The CICRF thus provides valuable or stabilizing financial and emotional relief for families facing incredible life challenges.

“When parents have kids with disabilities , the path is full of obstacles, but thanks to people like you, can make a possible dream come true. Our sincere appreciation and gratitude for the funds we received. Thanks for this big blessing. This help made a very significant and positive impact in our daily life.”

-Recipient Family

## **II. CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND PROGRAM**

### **Eligibility**

In order for a family to be eligible for assistance, they must have a child who:

- Is 18 years of age or younger
- Is a Massachusetts resident
- Is under the care of a licensed health care provider who has staff privileges at a hospital which is licensed or accredited to provide pediatric or neonatal care
- Has catastrophic medical or medically related expenses (defined as annual out-of-pocket expenses totaling more than 10% of the first \$100,000 of the family’s income plus 15% of any income in excess of \$100,000, after all other avenues of reimbursement have been exhausted)

### **Eligible Services**

The CICRF has a strong bias toward helping children to remain at home in their communities. It therefore considers reimbursement to families for a broad range of medical and medically related services and expenses that may not be reimbursable under traditional health insurance policies, or for which the family does not have coverage, including but not limited to:

- Physician’s expenses

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<sup>1</sup>D.U. Himmelstein, E. Warren, D. Thorne, S. Woolhandler. Market Watch: Illness and Injury as Contributors to Bankruptcy. Health Affairs – Web Exclusive. 2005 Feb 2; W5: 63-73. Epub 2005 Feb. 2.

- Specialized pediatric ambulatory care (testing, laboratory work, etc.)
- Acute or specialized hospital care, both inpatient and outpatient
- Rehabilitative therapies
- Medical equipment and supplies
- Medications
- Medically related home and vehicle modifications
- Health enabling services and equipment
- Related travel expenses such as mileage, food and lodging
- Funeral expenses
- Insurance co-payments and deductibles
- CommonHealth premiums

Following a special review, experimental treatment or medications, assistive technology, alternative or complementary treatment, home health care and other medically related services may be considered for reimbursement.

### **Commission Responsibilities**

The CICRF Commission consists of eleven (11) members, including [designees of] the Secretary of Health and Human Services, the Commissioner of Public Health, the Commissioner of Insurance, the State Treasurer and seven public members (including a representative of the AFL-CIO and at least two providers of health care services to children in Massachusetts). The Commission is responsible for establishing the policies and procedures necessary for administration of the CICRF, including application to the Fund, application review, determination of eligibility for services, and reimbursement.

The Department of Public Health is responsible for the general management and administration of the program, including maintaining confidential records for each child, determining eligibility and the amount of reimbursement, and preparing application or case materials for review by the entire Commission. **The Commission's goal is to act in the best interest of the child while ensuring that the Fund remains the payor of last resort.** Department of Public Health staff devote significant resources to case management and referral activities. If, upon review of an application, the applicant is found to be potentially eligible for funding through other sources or programs, Department of Public Health staff assist the applicant in applying for alternate benefits and resources.

"We really appreciate all the help from Catastrophic Illness In Children Relief Fund. We are very grateful to you for helping us at this most difficult time."

-Recipient Family

### III. DATA

#### Fund Accomplishments and Highlights

**Since the CICRF was established in FY 2001, the Fund has provided \$5.5M in reimbursements to 405 Massachusetts families with catastrophic medical or medically related expenses. It has proven to be an invaluable resource for families struggling with the need to preserve family life in the face of unbearable financial obligations.** The Fund has assisted families from a variety of income levels with a wide range of awards in proportion to their need. Payments to an individual family for fiscal year 2005 ranged from a low of \$30.72 to a high of \$39,692.23<sup>2</sup>. Many families have been eligible to receive CICRF assistance over multiple years.

“These funds will truly be a huge help to my family...the staff that we worked with was always so professional, helpful and respectful of our situation. I just want to express to you our gratitude for all your hard work on our behalf and on our children’s behalf.”

- Recipient Family

#### Diagnoses

The CICRF provides support for children with a wide variety of serious medical conditions. The broad categories of diagnoses of CICRF applicants include neuromuscular disorders (such as cerebral palsy), genetic and metabolic conditions, cancers, neurodevelopmental disorders, and traumatic injuries. Most of these diagnoses have a number of associated conditions that dramatically impact the lives of the children who have them. Examples of associated conditions include seizure disorders, vision and hearing loss, incontinence, and inability to eat safely by mouth. Oftentimes children with these challenges are entirely dependent on others for aspects of daily living, such as getting dressed, toileting, or even rolling over in bed. Many use wheelchairs or have substantial mobility impairments. The scope of impact of these medical conditions on the quality of life of the children and families who apply for support from CICRF cannot be overstated.

The charts<sup>3</sup> below portray the variety of conditions of the children assisted by the CICRF. The single largest category of conditions for which the Fund has provided children and their families with support is cerebral palsy and related disorders. Many of the conditions are chronic and require significant, ongoing medical care and/or pharmaceutical regimens. Other conditions severely impact mobility, confronting the families with the

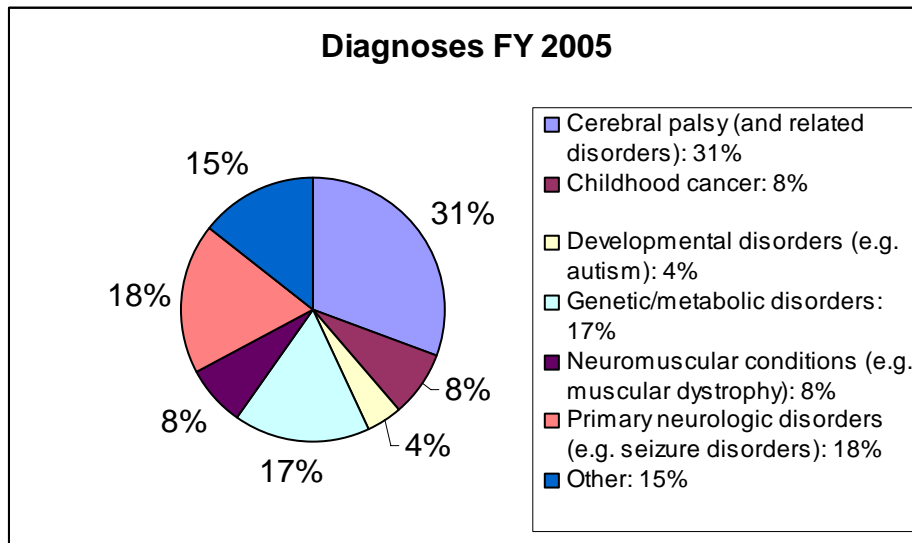
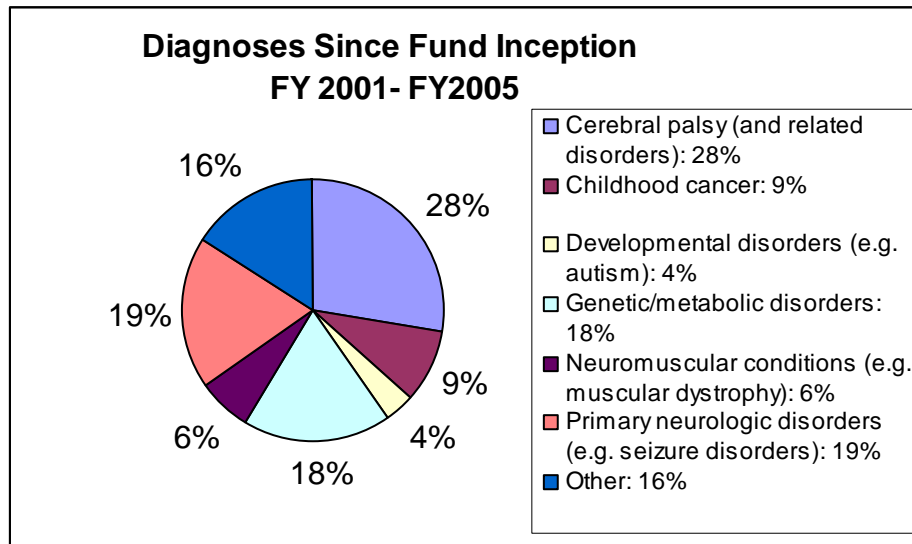
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<sup>2</sup> For some families, a majority of the reimbursements were received in a prior fiscal year. For others, payment in FY 05 could include expenses incurred over several years.

<sup>3</sup> For all FY01-FY05 charts, the total number of children is 405; for all FY05 chart, the total number of children is 186. All data are derived from the Massachusetts Department of Public Health Catastrophic Illness in Children Relief Fund database, Center for Community Health, 2006



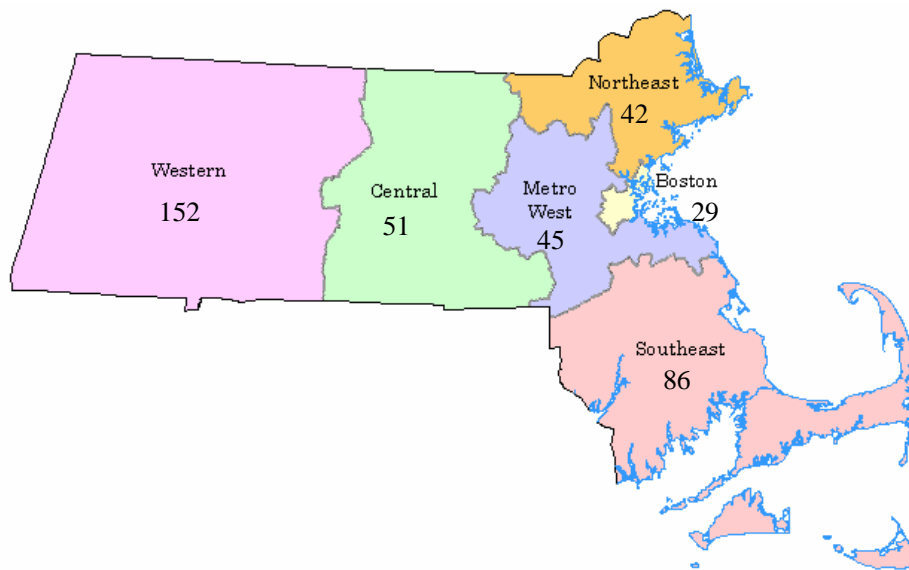
need to make their living space and modes of transportation accessible to the child, making it easier for them to maintain community-based care and remain living at home.



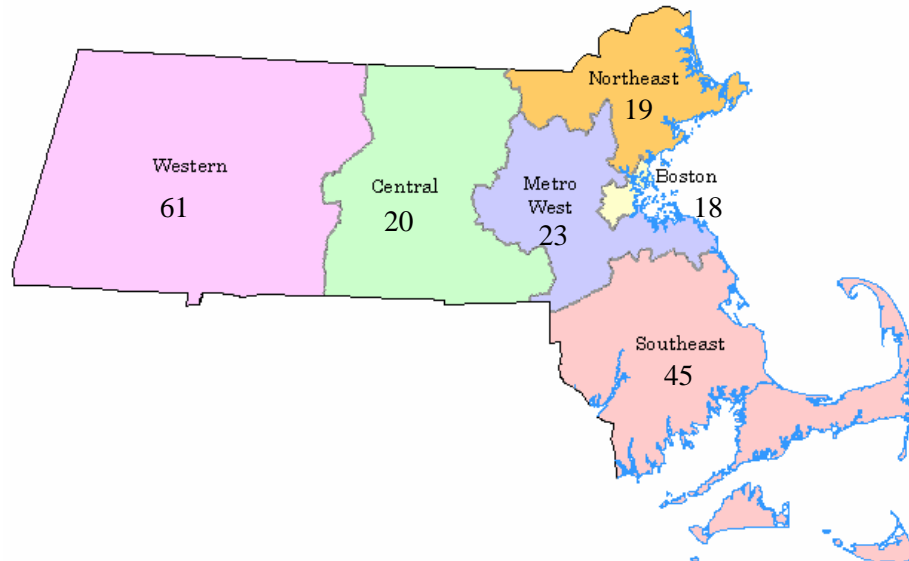
## Geography

The CICRF serves children and families from across all regions of Massachusetts. Fund staff conducts outreach activities on an ongoing basis, as evidenced by the use of the CICRF's services in each of the Department of Public Health regions. The majority of the children served are located outside of the Greater Boston area, and often must travel to Boston to receive specialized care (a significant family expense when many visits or hospitalizations are required). The maps below show the number of families in each region since the Fund's inception and for FY 2005, respectively.

**Families Served—Since Fund Inception  
FY2001-FY2005**



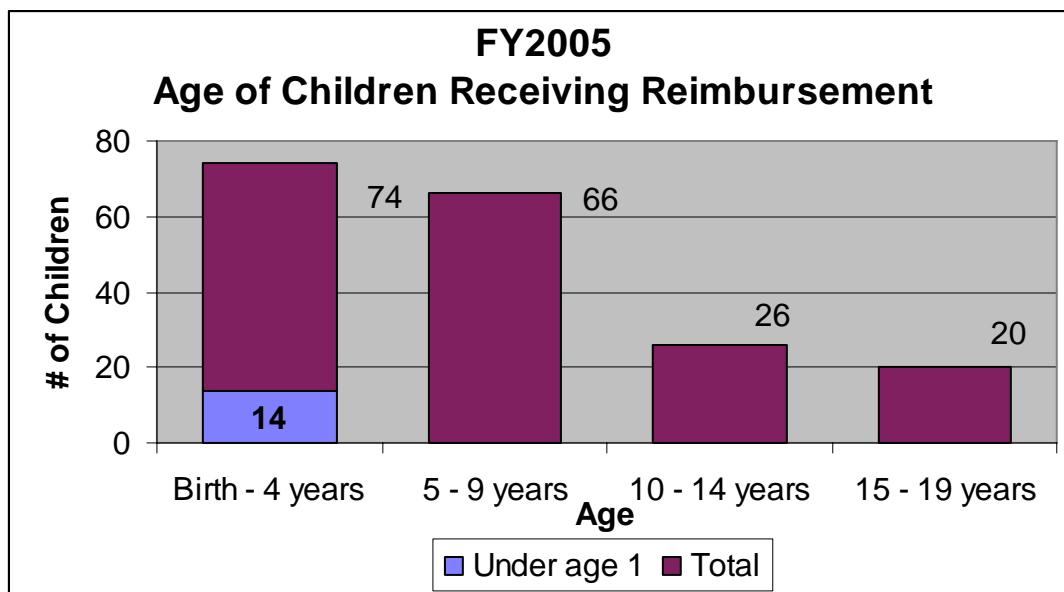
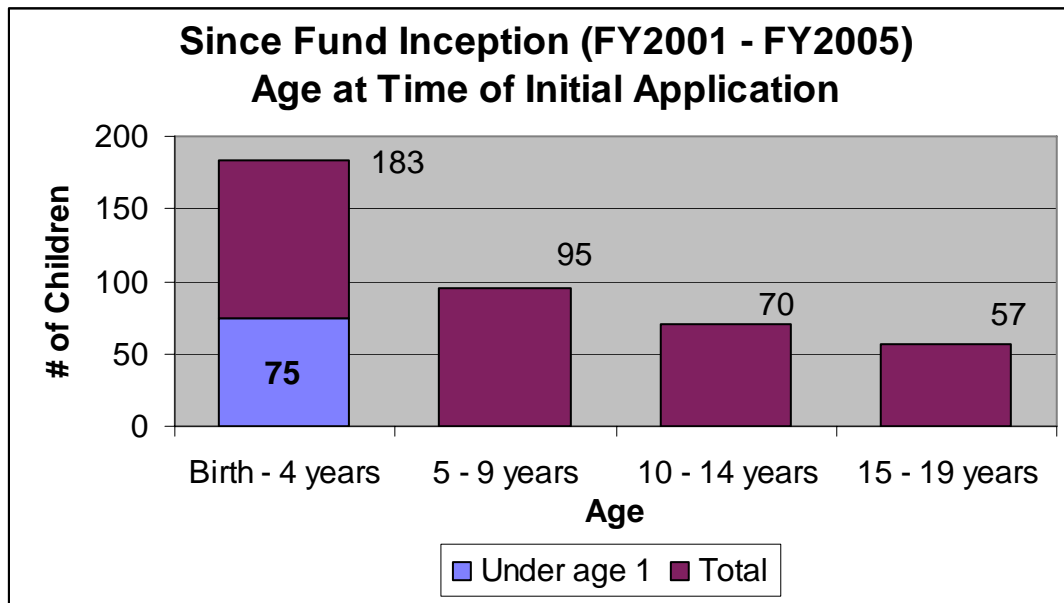
**Families Served—FY 2005**



## Age

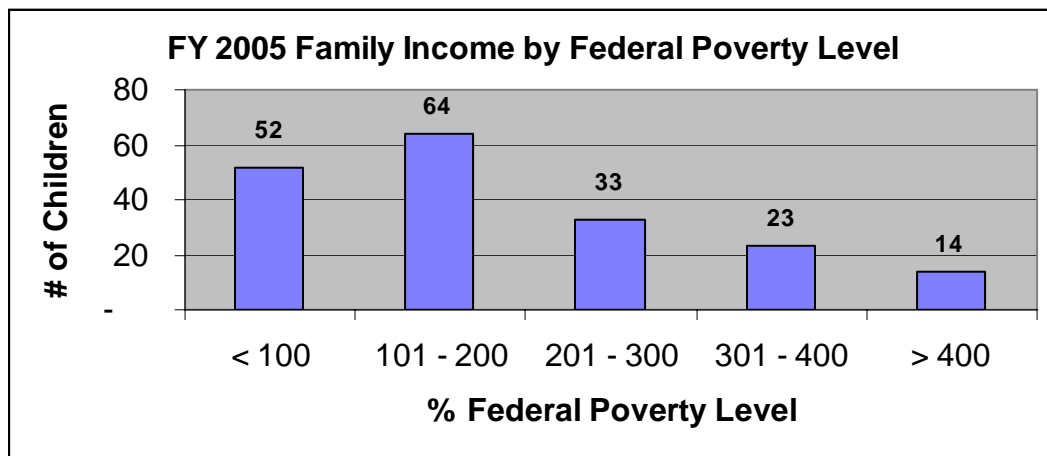
Forty percent of the children reimbursed in Fiscal Year 2005 were under age 5, and thirty-five percent were between age 5 and age 9. Fourteen percent of the children served in Fiscal Year 2005 were between age ten and age fourteen, and eleven percent of the children served were between age fifteen and nineteen.

The percent of children five to nine has increased from twenty-three percent to thirty-five percent since Fiscal Year 2004. The charts below show the breakout of children's age at time of initial application since fund inception, as well as the children reimbursed in Fiscal Year 2005 grouped by age.



## Income Level

The majority of families helped by the CICRF are extremely low-income and have limited, if any, access to other resources. Often a family with a catastrophically ill child has large, immediate expenses, which, in conjunction with their low-income level, make traditional loans unavailable. For these families, the Fund represents a major and sometimes sole source of hope and support.



“Thank you so much for your kind understanding and generosity. Having to deal with all these medical issues has definitely taken a toll on us. Thanks to the Fund, we have been able to keep our house and pay many overdue bills.  
-Recipient Family

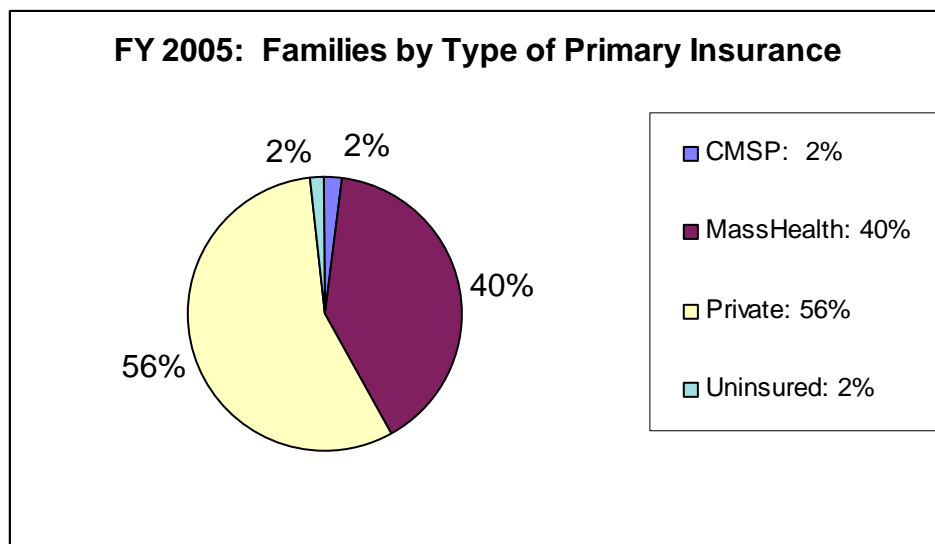
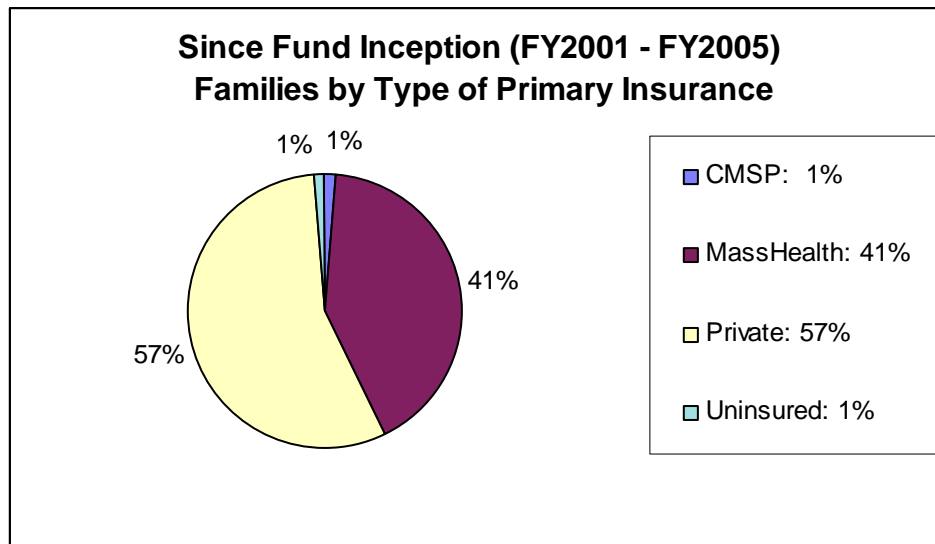
“I know it’s your job to help families with extraordinary special needs as ours but I feel as though you really enjoy making their lives a little easier.”

- Recipient Family

## Insurance Status

Ninety-eight percent of the children assisted by the CICRF in Fiscal Year 2005 had health insurance (fifty-six percent had private insurance and forty-two percent public insurance as their primary insurer); nevertheless these families still had catastrophic medical or medically related expenses, despite their coverage. Often this is because the insurance does not cover certain services or expenses. Other times, the expenses are so great that families reach benefit limits and are left to cope with the rest of the expenses themselves. The chart below identifies the primary insurance coverage of the families that have been reimbursed by the CICRF. In addition, many families (50%) have

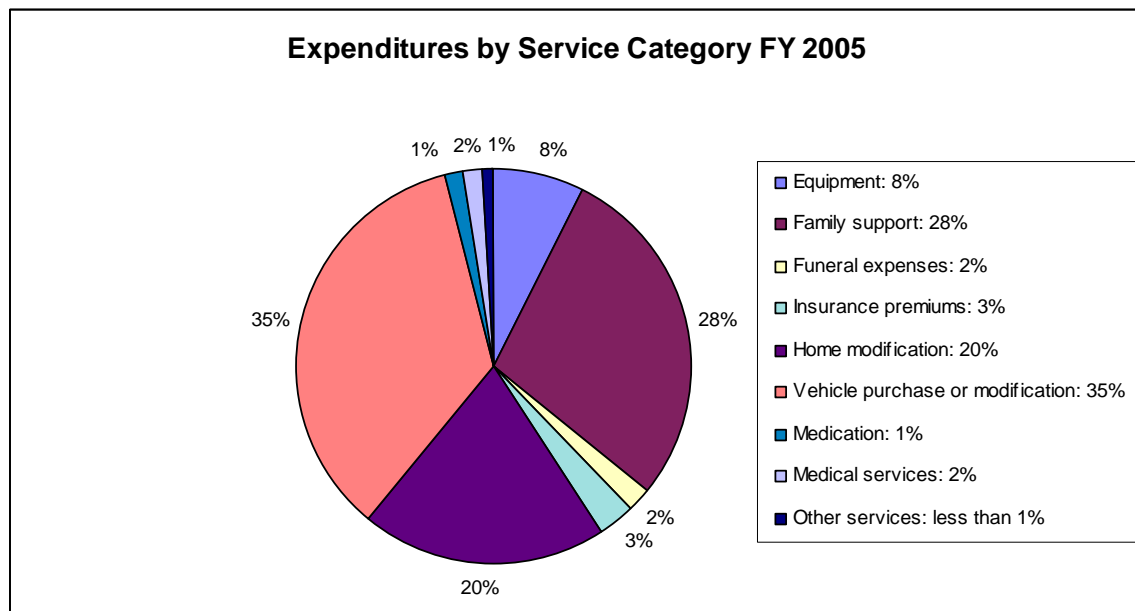
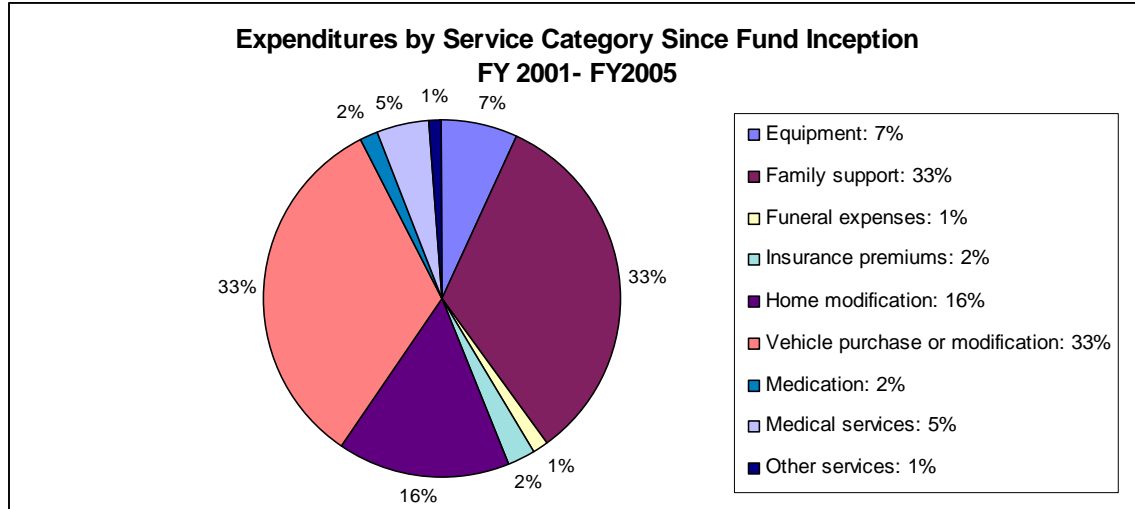
secondary Medicaid or CommonHealth coverage in order to supplement their primary insurance.



### Services Supported

The Fund reimburses families for a diverse set of medical or medically related services and expenses (see charts below for the distribution of these services). Examples of eligible expenses include medical supplies and equipment, such as wheelchairs; physical, occupational, and speech therapy; hospital and physician services; per diem travel expenses during inpatient hospitalizations; and some alternative or complementary treatments (depending upon an in-depth review by the Commission).

**The Commission supports families' decisions to care for their children in their homes.** Financial support from the Fund allows many families to avoid residential or institutional care, by enabling them to make structural or other modifications that are necessary in order to care for their child at home (such as a handicapped accessible bathroom or a wheelchair accessible home entrance/exit). The Fund also assists families that need a handicapped accessible vehicle to transport their child to medical visits within the community.<sup>4</sup>



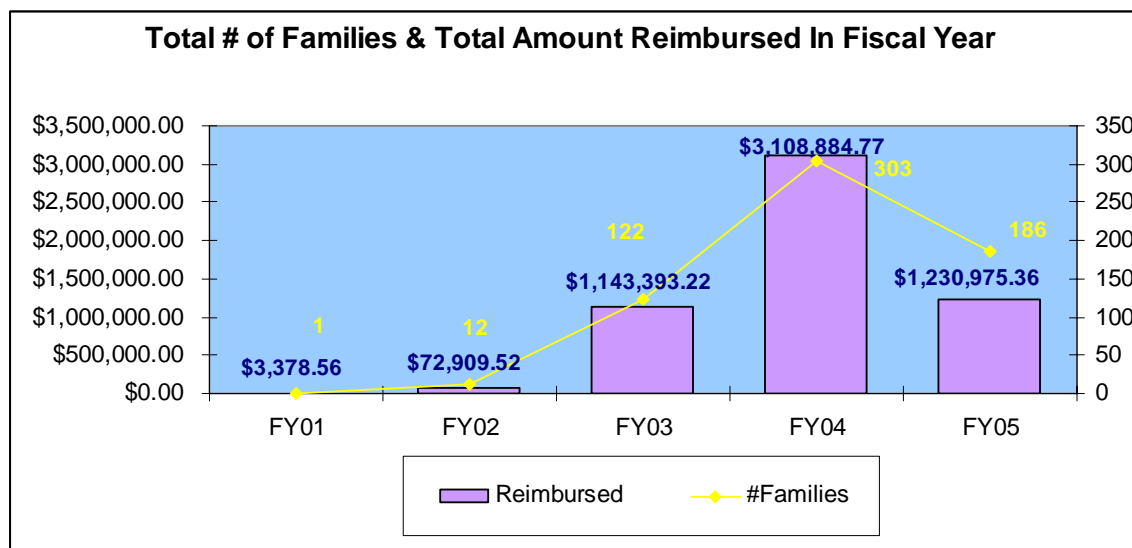
<sup>4</sup> Certain expenses, such as home and vehicle modifications, are reimbursed according to a sliding scale, and families have a lifetime limit on the number of these types of projects for which the Fund will reimburse.

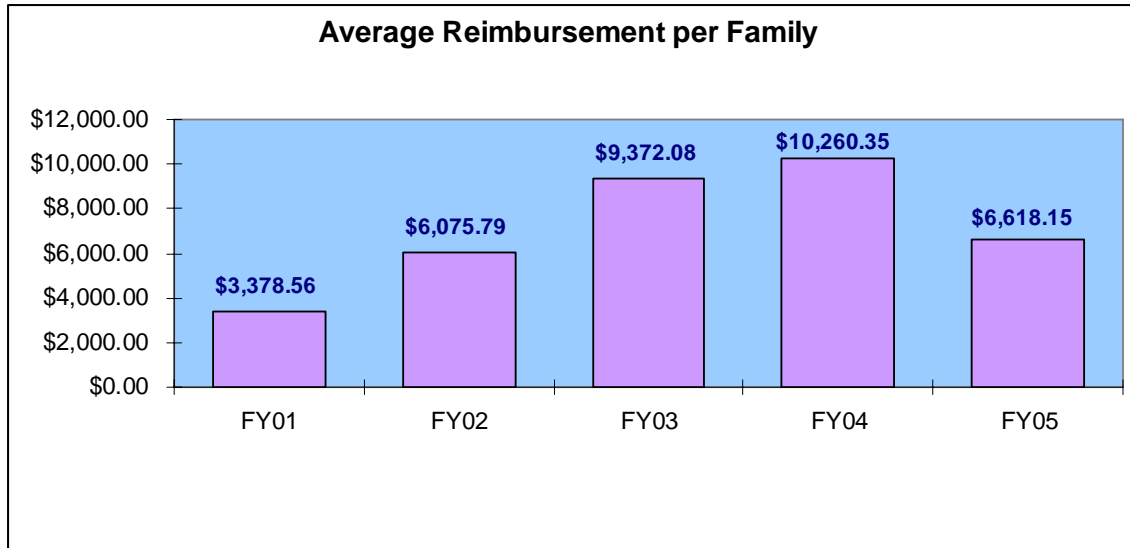
## Reimbursements to Families

Total reimbursements to families in Fiscal Year 2005 decreased from 2004. The fund paid families approximately \$1.2 M during the period from July 1, 2004 to June 30, 2005, which is much less than the \$3.1 M reimbursed to families in Fiscal Year 2004. Also, 186 families were reimbursed in FY 2005, a decrease from the 303 families reimbursed in the previous year. In addition, the average reimbursement per family dropped from over \$10,000 per family to \$6,618 per family in FY 2005.

When Fiscal Year 2005 began in July 2004, the Fund and Commission faced many challenges that would ultimately impact the amount of funds that were distributed to families:

- Funds from the Medical Security Trust Fund were slow in coming and some deposits were not made at all because of uncertainty about the funding of the Division of Employment and Training.
- The cap on use of administrative expenses from the Fund led to a lack of staff resources to perform the work of the Fund. Over time, this resulted in a backlog of applications from families that remained unprocessed and unfunded until February 2005 resulting in lower total reimbursements for the FY 2005.
- The Commission further refined its policy regarding requiring an identifiable twelve-month period of expenses that the Fund can use to reimburse expenses. This more accurately reflected the burden families incurred during a given year and in some cases reduced the reimbursement level.





#### IV. REVENUE AND EXPENDITURES

The CICRF is funded by quarterly transfers made from the Medical Security Trust, if funds are available after other obligations of the Trust are met<sup>5</sup>. During the Fund's initial years of service, there were significant remaining funds at the close of the fiscal year, as the Fund was still fairly unknown and underutilized. As knowledge and utilization of the Fund has increased, the expenditures have increased to match the need.

During FY 2003 and FY 2004 the Fund did not receive the full amount of anticipated transfers from the Medical Security Trust. In fact, during FY 2004 no transfers were made (additional deposits were the result of interest payments). Although this shortfall was offset by the surplus from the Fund's first three years, it poses a significant problem for the future if requisite funding is not received. Please see the table below for a complete breakdown of annual revenue and expenditures.

	<u>FY01</u>	<u>FY02</u>	<u>FY03</u>	<u>FY04</u>	<u>FY05</u>
<b>Balance from Prior Fiscal Year:</b>	-----	\$2,699,888	\$5,099,010	\$4,611,274	\$1,486,769
<b>Deposits (including interest):</b>	\$2,762,950	\$2,519,271	\$720,771	\$47,260	\$2,606,335
<b>Expenditures:</b>	\$63,062	\$120,149	\$1,208,507	\$3,171,764	\$1,242,563
<b>Balance Forwarded to Next Fiscal Year:</b>	\$2,699,888	\$5,099,010	\$4,611,274	\$1,486,769	\$2,850,541

<sup>5</sup> Chapter 111K, Section 9 of the Massachusetts General Laws provides that funding is to come through an employer's contribution to the office of employment and training, as \$1 annually for each employee "whose wages determine such employer's total unemployment health insurance contribution" under Chapter 151A section 14G of the General Laws.



## V. CONCLUSION

The Catastrophic Illness in Children Relief Fund does a reasonably good job of providing significant support to many families of children with a variety of different of health conditions and special health care needs throughout Massachusetts. The Fund allows children with significant health problems to remain with their families and as a part of their communities. In addition, the illnesses or injuries of the children that the Fund assists demand a wide range of medical services.

Given the number of children with special health care needs in the state, however, it is certain that the Fund could assist many more families by engaging in increased outreach, but its ability to increase marketing efforts and process more applications is constrained by limited staffing levels. Families served by the Fund generally appear satisfied with the assistance they receive, but it is likely that the population reached by the Fund is just a small subset of those Massachusetts families who are experiencing tremendous financial hardship due to their child's medical condition.

The diverse needs the Fund encounters attest to the value of this unique safety net. Ultimately, the Fund serves to improve the quality of life for many children and their families.

"I cannot thank you enough for helping me through the hardest battle of my life."

-Recipient Family

## COMMISSION MEMBER LIST

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